

An aerial photograph of a park in the London Borough of Tower Hamlets. The central feature is a large, abstract sculpture made of four vertical, cylindrical pillars of varying heights, painted in shades of blue and white, with patches of green moss or lichen. A wide, curved wooden walkway with a metal railing runs horizontally across the middle of the image, passing between the pillars. The surrounding area is filled with dense green trees and foliage. The text 'FEELING SEEN, HEARD AND CARED FOR IN THE LONDON BOROUGH OF TOWER HAMLETS' is overlaid in the upper right quadrant.

**FEELING SEEN,
HEARD AND CARED
FOR IN THE LONDON
BOROUGH OF
TOWER HAMLETS**

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WHO AM I?

Job title:
Employment status:
Identifying label:
Roles:
Duties:
Demographic:
Age:
Ethnicity:
Living arrangements:
Diagnoses:
Symptoms:
Salary bracket:

Carer duties:
Postcode:
Qualifications:
Marital/relationship status:
Number of dependents:
Work experience:
Car I drive:
Fitness routine/discipline:
Homeowner:
Benefits claimed:
Criminal record:
Right to work in the UK:

Years in industry/post:
Service user:
Dress code:
Accent:
Awards:
Colloquialisms:
Elocution, articulation and English
grammar:
Vocabulary:
Etc.:
Etc.:
Etc.:

IT SHOULD HAVE ZERO RELEVANCE. BUT DOES IT?

OUR TITLES AND DEMOGRAPHICS OFTEN PRESENT INFORMATION THAT IS AT RISK OF IMMEDIATELY PUTTING US INTO A BOX AND UNDER CONSCIOUS AND/OR SUBCONSCIOUS BIAS. THIS MAY BE OF ASSUMED HIERARCHICAL AUTHORITY/POWER – BUT MORE COMMONLY WHEN REGULARLY PARTICIPATING LIKE THIS FREE OF ANY CHARGE OR AS PART OF OUR “JOB” – A LACK THEROF.



**UNPAID CARERS
SAVE THE ECONOMY
£132,000,000,000
BILLION POUNDS
PER YEAR***

HOW IS THE BOROUGH REALLY COMING TOGETHER AND SUPPORTING THE LIVES OF THESE INDIVIDUALS?
IN A TANGIBLE AND MEASURABLE WAY.

*Source:CarersUK

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OUTLINE



1. MY EXPERIENCE OF TOWER HAMLETS HEALTH AND WELLBEING BOARD SO FAR.

2. FEEDBACK: OUR RECENT EXPERIENCES OF BEING CARERS IN TOWER HAMLETS.

3. IDEAS: FOR INDIVIDUAL UNPAID CARERS – NOT LINKED TO “ADULT SOCIAL CARE”.

6. ACTION ALREADY DRIVING CHANGE I AM INVOLVED IN RIGHT NOW.

5. SUCCESSFUL MODELS OF SOME SUPPORT ALREADY WORKING IN TOWER HAMLETS.

4. CONSIDERATIONS FOR THE STRATEGY.



**"I FEEL LIKE I
HAVE BEEN
BEHIND A ONE-
WAY MIRROR AT
THIS BOARD
FOR NEARLY
THREE YEARS."**

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PRESENTER NOTES FROM PREVIOUS SLIDE

- Attending TH Health and Wellbeing Board meetings for up to three years.
 - Active participant on most meetings I have attended.
 - Would send in questions beforehand, would sit through two hours of the call and they would not be answered.
 - Only able to communicate if I was in the chat or unmuted myself – which I am now told I will not have access to after today.
 - Was told I would be contacted and kept in the conversation around the strategy via means of “co-production”.
 - Was not.
- Previous three-year strategy has not even one mention of the word “carer” or “carers” (I did a Ctrl+F search).
- Welcomed for a 1:1 with the Chair Cllr. Rachel Blake where I mentioned that I wanted to be involved in for the drafting and was reassured I can and would be. But am now being told that this is not a space for co-production? – this is why I have been optimistically attending for all of these years.
- Current draft summary still no mention of “carer” or “carers” (I did a Ctrl+F search again).– this is not the same as “social care”. We are individuals outside of their register.
- The draft consultation is out and I have not had one conversation with anyone about what went in it. We should have been involved way before this. Why is the Board meeting open to the public? Is it a legal requirement or an obligatory lip service? I have still been left out of all important discussions. I feel I am watching the meeting through a one-way mirror with speakers but no microphone – I am not “at the table” – which I was abruptly reminded yesterday too when told I will no longer have the MS Teams link – and should instead channel my feedback through Healthwatch Tower Hamlets (another finger-pointing attitude and being bounced around the houses).
- I contacted Healthwatch Tower Hamlets who told me they do not have any projects for carers at the moment and their focus is disabled residents. – of which they will surely need carer help, no? – and again – for free?
- If we are meant to be involved via true co-production elsewhere, where? How? There were many opportunities for me to have received this information since I started attending this Board but I was not provided with it and feel strung along and am faced with very Politician-type defensive responses.
- I am very glad that I had this opportunity to express my experiences this evening instead of this agenda item being a glossy hand-picked successful, but not largely representative, resident/service-user experience.

I AM NOT HERE TO FIGHT. COMPLAIN OR BE A MOANING MOSQUITO IN ANYONE’S EAR. NOBODY OR NO ORGANISATION CAN SATISFY EVERYONE, IN EVERY WAY, ALL THE TIME.
CHOOSE CAREFULLY WHAT YOU SAY. SAY WHAT YOU MEAN. MEAN WHAT YOU SAY.
WHEN YOU CANNOT DELIVER FOR ANY REASON AFTER A PROMISE. COMMUNICATE CLEARLY WHY AND WHAT THE ADJUSTED PLAN IS.

WHAT HAS BEEN/WAS GOOD ENOUGH IN THE BOROUGH FOR SOME CARERS?

~~1. Rethink Mental Illness Carers Support Group. - DECOMMISSIONED~~

2. Breathing Space at the Buddhist Centre.
3. Emotional support and training by Katherine and Catherine through Coaching for Unpaid Carers.
4. The New You Coaching Programme by Ruth Pearson through Working for Carers Trust.
5. Emotional First Aid Classes from TH Children and Culture Directorate .
6. Tower Hamlets Carers Centre (only partially satisfactory).
7. Community Mental Health Transformation Programme and People Participation at NHS ELFT.

COMMUNITY FEEDBACK FROM CARERS IN TOWER HAMLETS



"I DON'T ACTUALLY KNOW WHAT TOWER HAMLETS DO FOR CARERS TO BE ABLE TO EVEN COMMENT."

"WHAT ARE THEY ACTUALLY DOING OTHER THAN SENDING US IN PAINSTAKING CIRCLES?!"

"TICKBOX PROCESS TO HAVE US THERE BUT THEN NOTHING HAPPENS – IT'S RUDE."

"WHAT IS A CARERS ASSESSMENT?...I DON'T THINK I HAVE HAD ONE."

"STOP TELLING FAMILIES TO DO MORE. WE ARE ALREADY SO EXHAUSTED!"

"YOU DON'T WANT US TO SPEAK ON THEIR BEHALF OR VALUE OUR COMMENTS BUT YOU ARE VERY QUICK TO HAND THEM BACK TO US TO GO HOME – AS IF I AM SUDDENLY COMPETENT?"

"COULD YOU HAVE SOME RESPECT? HE JUST DIED AND YOU ARE HERE COLLECTING HOMECARE EQUIPMENT. ARE YOU EVEN HUMAN?"

"STOP USING CONFIDENTIALITY AS A DETERRENT TO WHAT IS IN THE BEST INTERESTS OF MY CARED-FOR."

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CARER FEEDBACK ABOUT TOWER HAMLETS CARERS CENTRE

"EVERY ENCOUNTER I HAVE HAD THERE, HAS BEEN BAD."

"PERSON WAS NOT INTERESTED IN ME AS AN INDIVIDUAL AT ALL. NOT INTERESTED IN ME AS A CARER."

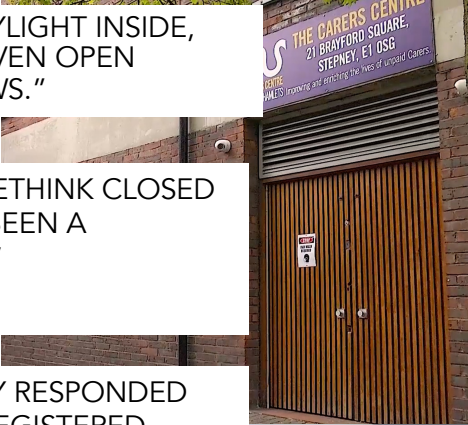
"THE PHYSICAL SPACE IS GRIM. DOES NOT FEEL LIKE SOMEWHERE YOU ARE GOING TO BE HELD."

"NO DAYLIGHT INSIDE, CAN'T EVEN OPEN WINDOWS."

"AFTER RETHINK CLOSED – IT HAS BEEN A LIFELINE."

"NOBODY RESPONDED WHEN I REGISTERED ONLINE."

"THE MESSAGES AND RETREATS ARE NICE."



INSIGHT, INTEL AND REQUESTS FOR THE TOWER HAMLETS HEALTH AND WELLBEING STRATEGY

VISIBILITY & QUALITY

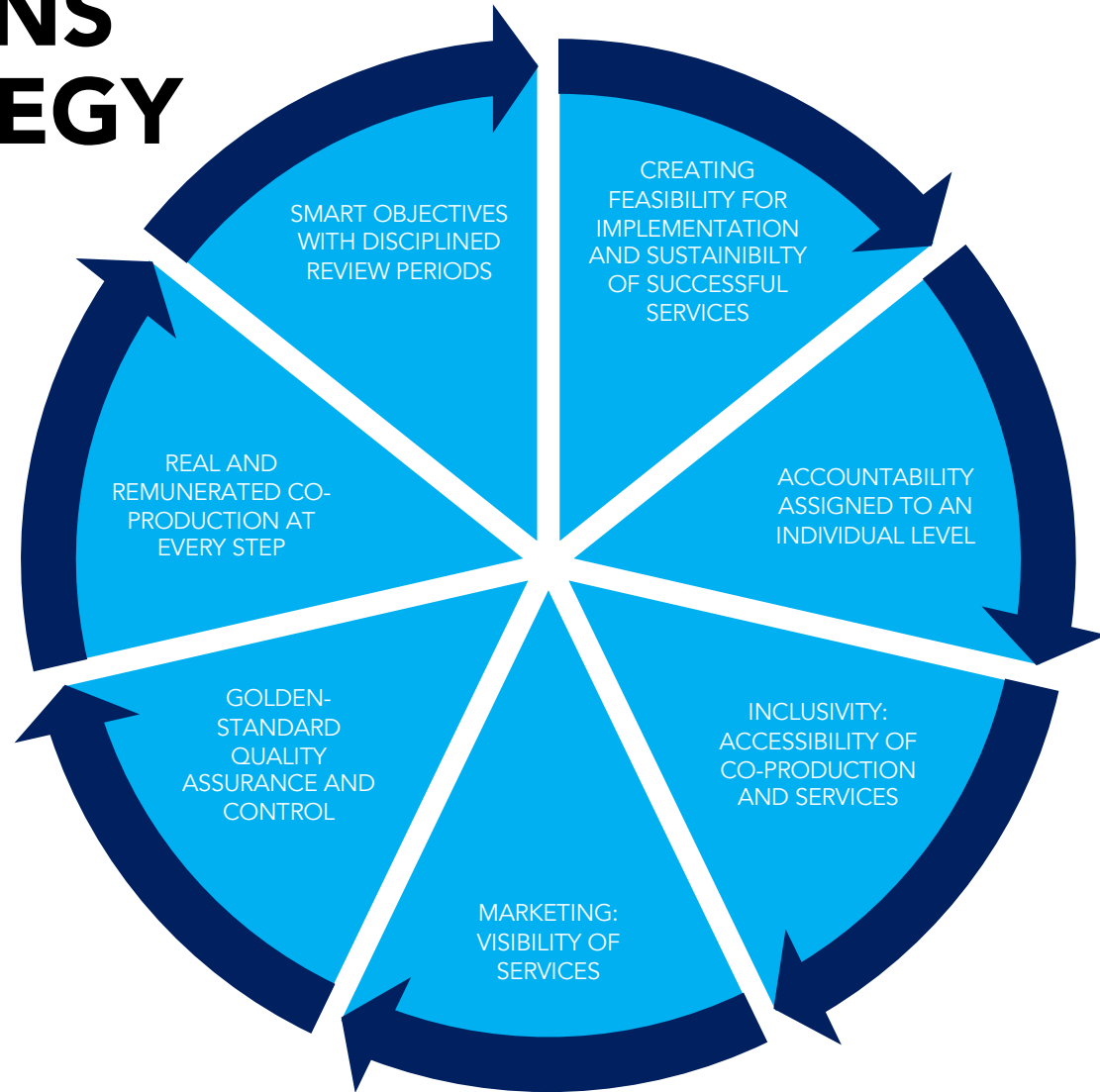
A SERIOUS STRATEGY TO IDENTIFY ADULT CARERS AND YOUNG CARERS.

- Why are we waiting for crisis point please? - At which point services, referrals and email inboxes are oversubscribed leaving many in crisis alone.
- A process to identify those in distress or at risk of ill health and wellbeing before they even need to call their GP.

THOROUGH, CO-WRITTEN AND CO-PRODUCED CARER ASSESSMENTS AND CARER SUPPORT PLANS.

- Is our menu of services, support and signposts enough - and of a high enough quality - to answer at least the most common areas of ill health and wellbeing in the Borough?
- How have we measured this? E.g Tower Hamlets have re-directed those Carers that were being heavily supported by Rethink Mental Illness Carer Support Group to Tower Hamlets Carers Centre. Have you asked Carers if they feel this pivoted signpost is good enough? I have. And many have said **"No"**.

CONSIDERATIONS FOR THE STRATEGY



STRATEGY SUGGESTIONS

INDIVIDUAL STAFF MEMBERS NAMED AND ACCOUNTABLE AS THE CONTACT PERSON FOR EACH SMART AMBITION AND DELIVERABLE

AMBITIONS TO BE PRESENTED AS SMART OBJECTIVES – CURRENTLY SOUND ATTRACTIVE BUT RATHER VAGUE AND SWEEPING

TRAUMA-
INFORMED
TRAINING FOR
ALL STAFF

SIGNIFICANT COVERAGE ON MENTAL HEALTH AS A STANDALONE AMBITION IF WE ARE SERIOUS ABOUT IT. I AM BEING SIGNPOSTED TO ANOTHER ALLEGEDLY LIVE AND SIGNIFICANT STRATEGY? IS IT PUBLIC?

BUDGETS ALLOCATED FOR ACTUAL, TANGIBLE, AND **SATISFACTORY** SERVICES FOR SUPPORTING THE MENTAL HEALTH AND LIVELIHOODS OF CARERS

SIGNIFICANT STRATEGY AND RESOURCES ASSIGNED TO SUPPORT THE BOROUGH'S NEW "BLENDED TEAMS" AND MOST UNSUPPORTED GROUPS

SUPPORT FOR INDIVIDUALS WANTING TO TAKE PART. E.G. HOW MY PAYMENTS WILL AFFECT MY BENEFITS AND HOW TO SEND AN EMAIL OR ALTERNATIVE

An aerial photograph of a dense green forest with a winding gravel road. In the center, there is a white text box with the question "WHAT ELSE NEEDS ADDRESSING?". Surrounding this central box are eight arrows pointing outwards, four on each side. The left side has four red arrows pointing left, and the right side has four green arrows pointing right. Each arrow contains a specific text point.

**WHAT ELSE
NEEDS
ADDRESSING?**

BORDERLINE EXPLOITING
"COMMUNITY MEMBERS"
TO HELP YOU FOR FREE

BEING LABELLED AND
BRANDED AS A
CARER/UNEMPLOYED

INVISIBLE, DISMISSED,
ABANDONED

ALIENATING ME OUT OF THE
DECISIONS ON MY
CARED-FOR

SATISFACTORY REWARD
AND RECOGNITION FOR
"COMMUNITY
COLLEAGUES"

BEING SEEN AS AN
INDIVIDUAL WITH
INDIVIDUAL NEEDS
AND DESIRES

REGULAR,
COMPASSIONATE AND
TRAUMA-INFORMED
SERVICE AND CARE

ALLOW CARERS TO HAVE
SIGNIFICANT SAY EVEN
WHEN THE CARED FOR HAVE
CAPACITY OR ARE OVER 18.

**ORGANISATIONS
THAT ALREADY
REMUNERATE
PARTICIPANTS
FOR CO-
PRODUCTION,
CO-FACILITATION
AND ATTENDING
UP-SKILLING
TRAINING.**

- WORKING WELL TRUST

- THE COMMUNITY MENTAL
HEALTH TRANSFORMATION
PROGRAMME AT NHS EAST
LONDON FOUNDATION TRUST
(ELFT)

- PEOPLE PARTICIPATION AT
NHS ELFT

- CO-CREATE TOWER HAMLETS
(CO-FACILITATION)

- MIND AND THE SUN NETWORK
(PROVIDE VOUCHERS)

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**WHAT I AM
DOING NEXT
TO DRIVE
CHANGE FOR
CARER
WELLBEING?**

PEOPLE PARTICIPATION CARERS WORKING TOGETHER GROUP

JOIN US TO SHAPE MENTAL HEALTH SERVICES IN YOUR LOCAL AREA. PART OF THE COMMUNITY MENTAL HEALTH TRANSFORMATION PROGRAMME AT NHS EAST LONDON FOUNDATION TRUST.

Become our Community Colleagues in Tower Hamlets, Newham or City & Hackney.

Friday 16th July

1.30pm- 3.00pm online zoom drop in session.

Email: heena.patel20@nhs.net

Eligibility rules may apply for participation payments.

**THANK YOU.
QUESTIONS**

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CREDITS, MENTIONS AND THANK YOU'S

Clare Burges

Sharron Currie

Anonymous Carer

Anonymous Carer

Community Mental Health Transformation Programme

NHS ELFT People Participation Team

Working Well Trust

Carers UK

Patricia Rangel – CoCreate Tower Hamlets

All other wonderful Carers, Friends, Family and supporters of me and my work